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Award Number: DAMD17-00-1-0493

TITLE: Factors Affecting African American Women's Participation
in Breast Cancer Screening Programs: A Qualitative Study of
Uninsured Low Income Women

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REPORT DATE: August 2001

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
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*Form Approved
OMB No. 074-0188*

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

1. AGENCY USE ONLY (Leave blank)	2. REPORT DATE	3. REPORT TYPE AND DATES COVERED
	August 2001	Annual (10 Jul 00 - 9 Jul 01)
4. TITLE AND SUBTITLE Factors Affecting African American Women's Participation in Breast Cancer Screening Programs: A Qualitative Study of Uninsured Low Income Women		5. FUNDING NUMBERS DAMD17-00-1-0493
6. AUTHOR(S) Frances M. Lewis, Ph.D.		
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of Washington Seattle, Washington 98105-6613 E-Mail: <u>fmlewis@u.washington.edu</u>		8. PERFORMING ORGANIZATION REPORT NUMBER
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSORING / MONITORING AGENCY REPORT NUMBER
11. SUPPLEMENTARY NOTES		
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited		12b. DISTRIBUTION CODE

20011130 057

13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information)

Breast cancer screening programs offer the greatest promise for early detection but rates of participation in free screening programs have been disappointing for challenged populations. The purpose of the current study is to elaborate the beliefs and culturally embedded meanings that a population of low income, uninsured African American women hold toward breast cancer and breast cancer screening. During Year 01, the intermediary systematically attempted to contact 685 potentially eligible women from a population data base from the Breast and Cervical Health Program in Washington state. Of these, 318 women had non-functioning phone contact numbers. Another 175 women were successfully contacted by the study intermediary, 91 of whom were screened out as ineligible and 26 of whom refused participation. A total of 64 eligible women agreed to be contacted by a study interviewer, 9 of whom declined or were determined to be ineligible by the interviewer. Thirty-one (31) women were enrolled and completed the case intensive interview and an additional 24 eligible women agreed to be contacted by a study team interviewer and are pending enrollment. Quality monitoring has been instituted for data generation and transcription. Initial inductive coding has yielded findings not previously documented in the research literature.

14. Subject Terms (keywords previously assigned to proposal abstract or terms which apply to this award) breast cancer screening, cancer detection, community-based program behavioral science, qualitative research		15. NUMBER OF PAGES 31	
		16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited

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Introduction

Breast cancer screening programs hold the greatest promise for early detection of the disease. However, rates of participation in breast cancer screening programs, particularly in community-based samples, has been extremely disappointing for low income, uninsured African American women. The purpose of this Idea Grant is to describe and elaborate the perceptions, beliefs, and culturally embedded meanings that a population of low income, uninsured African American women hold toward breast cancer and breast cancer screening. There are two phases to the study: Phase 1 involves 170 case intensive interviews and Phase 2 involves four focus groups. Both phases involve a population-based sample of low income, uninsured African American women who were eligible for but declined to receive a free screening mammogram. Year 01 activities relate to only Phase 1 of the study; accomplishments in Year 01 are described next.

Body of Annual Report

In 2001, an estimated 192,200 women in the U.S. will be newly diagnosed with breast cancer (Greenlee, Hill-Harmon, Murray, & Thun, 2001). When diagnosed early, breast cancer is a curable disease. When the disease is confined to the breast, 10-year survival rates range from 65-80%. When diagnosed at a later stage (Stage 3 or 4), the 5-year survival rate is only 2-5%. Between 1993 and 1995, 48.1% of the new cases in African American women in Seattle-King County, the largest recruitment county for this study, were diagnosed at late stages compared to 32.4% in Whites (Washington State Cancer Registry Data, 1999).

Early hopes were held for increasing participation in breast cancer screening programs for low income, African American women when Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990. This act authorized the Centers

for Disease (CDC) to establish a national program entitled the National Breast and Cervical Cancer Early Detection program whose goal it is to ensure that women for whom screening was recommended receive regular screening and prompt follow up as needed (CDC, 1998). By guaranteeing access, the assumption was that stage at diagnosis would be similar for all populations of women (Zaloznik, 1995).

Although this national screening program has increased participation rates compared to pre-program levels, success rates are less than ideal. In Washington state in Seattle-King County, a substantial number of African American who were successfully reached through community outreach workers decided to not obtain a free screening mammogram. This means that variables other than free services and outreach were related to their participation rates in breast cancer screening programs.

Studies of populations outside of Washington state have also shown that African American women are more likely to be diagnosed with advanced (TNM Stage III or IV) disease at initial time of diagnosis than are Caucasian women (Jones, Kasl, Curnen, & others, 1995; Lannin, Mathews, Mitchell, & others, 1998). In a recent population-based study in Connecticut, African American women were diagnosed more commonly with later stage disease (age-adjusted odds ratio [OR]-2.01, 95% confidence interval) than were white women (Jones, Kasl, Curnen, & others, 1995). In a recent case-control study of African-American women, being African American significantly predicted diagnosis of advanced stage (odds ratio: 3.0, 95% confidence interval), as did having low income (OR, 3.7, CI 95%),as did being uninsured (OR 2.5; 95% CI) (Lannin, Mathews, Swanson, Swanson, & Edwards, 1998). Despite the link between early detection and cure, women do not always participate in breast cancer screening programs, even when they are accessible, available, and are offered free of charge to participants (Zaloznik, 1995). This is particularly true for African American women

compared to White women (McCarry, Yood, MacWilliam, & Lee, 1996.) See also Abbott & others, 1999; Adderley & Green, 1997; Bernstein, Mutschler, & Bernstein, 2000; Bowen & others, 1997; Burnett & others, 1995; Champion & Menon, 1997; Danigelis & others, 1995; Davis, 1998; Erwin & others, 1999; Lawson, 1998; McDonald & others, 1999; Miller & Champion, 1997; Phillips & others, 1999; Stoddard & others, 1998). Taken together, these statistics mean that participation in breast cancer screening programs is essential to the early diagnosis, disease-down staging, and the treatment of breast cancer for all women, particularly low income or uninsured African American women.

What we do know with the greatest confidence are those factors that predict utilization in women who participate in screening programs or who are diagnosed with breast cancer. See critical reviews by Hoffman-Goetz & Mills, 1997; Lowe & others, 1995.

Although knowledge of these factors is important, it tells us nothing about women who do NOT participate in breast cancer screening programs. That is, what we know that predicts utilization is based on studies of women who do indeed participate in these programs; they do not derive from studies of women who are eligible but do not participate! This constitutes a fatal flaw or fallacy in current research: We cannot and we should not assume that factors affecting utilization in women who obtain screening are the same factors that affect women who choose to not be screened.

It is precisely knowledge of the beliefs of non-participating African American women who are uninsured with low incomes that both clinicians and scientists need to know in order to mount successful screening programs. In the absence of such information, program planners are "shooting in the dark" to know what to say, how to say it, how to tailor the message in culturally appropriate terms, how to outreach the

women, or what to do to assist them to engage in the program (Mahloch, Thompson, & Taylor, 1998). Information from these eligible but non-participating women is essential for designing culturally sensitive and informed materials, outreach, media and channel messages (See Adderley-Kelly & Green, 1997; Ansell & Others, 1994; Brown & Williams, 1994; Crane & others, 1998; Eng, 1993; Erwin & Others, 1999; Kaluzny & Others, 1994; Mahloch & Others, 1998; Reynolds & Others, 1990; Rimer, 1994). In the absence of such information, clinicians and scientists alike will not know what to do to further the cancer control objectives of the nation.

The current study assumes that cultural and psychosocial variables, yet to be elaborated in the research literature, are factors that affect low participation rates in breast cancer screening programs for financially challenged and uninsured African American women. Additional research, like that being conducted in this Idea Grant, is clearly needed to describe the cultural and psychosocial factors that affect low participation in free screening programs. Only through such research can we begin to mount culturally and socially relevant programs for diverse and vulnerable populations of women whom we have continually failed to assist. The long-range goal of this study, beyond the funding period, is the development of culturally informed outreach messages, printed materials, and program messages that are responsive to the culturally embedded meanings and perceptions of fiscally challenged, uninsured African American women.

Statement of Work

The approved Statement of Work and each related activity is enumerated in Figure 1. See Figure 2 for the study's overall objectives.

Figure 1: Approved Statement of Work

1. Train outreach workers for protocol on inviting women into study.
2. Formalize linkages between recruitment sources and study team.
3. Establish linkages between outreach workers and interviewers and study team.
4. Develop spreadsheets for tracking target and accessed sample.
5. Identify target sample of women for interviews.
6. Convene Community Advisory Committee to pre-screen interview schedule.
7. Begin intermediary contact calls to eligible women.
8. Begin interviews by trained interviewrs.
9. Train Project Manager on open coding.
10. Begin weekly meetings of interview team.
11. Begin transcription of first set of interviews.
12. Begin open coding of interviews
13. Convene first meeting of Scientific Advisory Council.
14. Continue weekly meetings of interview team.
15. Convene second meeting of Scientific Advisory Council
16. Complete 56 interviews.

Figure 2: Overall Objectives of Study, Including Phase I and II

1. To conduct and audio-tape record case intensive interviews with 170 African American uninsured women of poverty who are drawn from a population data base of eligible women who were referred into but did not enroll in the breast cancer screening program in the Breast and Cervical Health Program in Washington state. [This is a Phase I activity.]
2. To use technical methods to inductively code and content analyze the transcribed audio-tapes from the interviews in order to identify factors associated with non-attendance in free breast cancer screening programs. [This is a Phase I activity.]
3. To conduct four focus groups involving a total of 32 African American women from the same population of uninsured fiscally challenged women in order to check the accuracy and thoroughness of the factors associated with non-participation that were identified from the coded interview data. [This is a Phase II activity and is not relevant to Year 01.]

Progress includes the hiring and training of the Research Manager; implementing the population data-based recruitment strategies; hiring and training the Interview Team; formation of the Community Advisory Committee; developing and implementing a quality monitoring program for the study interviews; and micro-managing operational details of both the accrual/refusal rates as well as the case intensive interviews, including data retrieval, tracking, and technical transcription. The numbered items in the

boxes of Statement of Work below correspond to the numbered activities and tasks in the approved Statement of Work in the funded grant application. Items of related work are linked together in the report that follows for ease of understanding.

STATEMENT OF WORK

1. Train outreach workers on protocol for inviting women into study.

STATUS: Accomplished.

The study team identified and trained a study intermediary who functions as an intermediary for all agencies. By using a centrally located intermediary, we increased the efficiency of the women's invitation into study and avoided possible coercion by the outreach workers. In this way, the outreach workers for the Breast & Cervical Health Program continued to do the outreach work while the centralized study intermediary contacted potentially eligible women.

Three one-day workshops were also held to train outreach workers and study team members on the operational aspects of verbal assent and signed informed consent and the role of the study intermediary. Many of the community-based personnel had no prior or had only limited experience in conducting a study; terms like signed informed consent and coercion were not familiar terms for many. Three training workshops have been conducted in Year 01 that educated the outreach workers on these distinctions and responsibilities. See below text for more specifics on the training workshop, including the Training Manual.

STATEMENT OF WORK

- 2 . Formalize linkages between recruitment sources (agencies subcontracted to outreach eligible women) and the investigative team.**
- 3. Establish linkages between outreach workers and interviewers and investigation team.**
- 6. Convene Community Advisory Council to pre-screen interview schedule for study.**

STATUS: Accomplished.

Under the leadership of both Phillips-Angeles and Song, formal linkages were established between the recruitment sources and the investigative team. Ms. Phillips-Angeles holds regularly scheduled meetings with the Breast and Cervical Health Program (BCHP) administrative and supervisory staff, thereby linking this grant with the personnel responsible for outreaching eligible women. In addition, and unique to this grant, a Community Advisory Committee was convened by the investigative team in order to establish additional and more intellectually intimate linkages between the recruitment sources and the investigative team.

Membership of the Community Advisory Committee (CAC) includes members and supervisors from the recruitment sources as well as additional stakeholders from the community, local, regional, and state-wide government and agencies. The composition of this Committee is essential to the on-going support and access to the study population as well as to the future dissemination of study findings into sustainable outreach activities and programs for fiscally challenged African American women. The site of the CAC meetings is at community health clinic sites or other user-friendly community based locations. Ms. Phillips-Angeles provides the leadership for these meetings and works with Lewis and Bunt and members of the advisory committee to set the agenda.

Initial recruitment to the CAC began with those members of the community who had worked in outreach and public health activities with low income, non-insured African American women; this included BCHP contracted outreach workers as well as clinic coordinators and members of the BHCP Community Partners group, including staff

from the main recruitment counties for BCHP, Pierce and Snohomish, as well as Seattle-King counties.

Initially, the Community Advisory Committee met monthly. Most recently, it has settled into quarterly meetings for 2001. Meetings are scheduled for every three months and will continue through Years 02 and 03 of this grant.

To date, the Community Advisory Committee has met six times after the initial meeting on April 14, 2000. At that first meeting, Phillips-Angeles and Lewis shared the text of the grant and invited full participation in the study. Specific ways to work together were explored, including opening up all grant line paid positions for consideration by community members. This initial meeting resulted in members self-selecting into the Community Advisory Committee, recommendations for additional members for the Community Advisory Committee, and the identification of persons for the interview team.

The establishment of this Community Advisory Committee is consistent with the community partnership model that underlies this Idea Grant (Flynn, 1992; Flynn & Others, 1991; Freudenberg & Others, 1995; Minkler & Wallerstein, 1997). The intent is that the community stakeholders, not merely the investigative team, own and be invested in all aspects of the data emanating from this study. Furthermore, by deeply engaging community members early in the implementation phase, the investigative team hoped there would be greater likelihood of program impact from the study.

The Community Advisory Committee has already contributed the following to advance the grant's work:

- ◆ Reviewed interview questions, recommended re-sequencing of questions, and tested the interview through mock-up [Pre-screening the interview schedule was a formal part of the Statement of Work for this grant.]

- ◆ Reviewed the recruitment text for culturally appropriate language
- ◆ Brainstormed outreach sites and approaches to expand access to eligible women
- ◆ Served as a source of recruitment for study team staff
- ◆ Recommended additional ways to show respect and consideration to study participants
- ◆ Offered media ideas for making the project visible to the community

Members of the Community Advisory Committee include Dr. Maxine Hays, M.D., Washington State Health Department; Cherie Minear, Program Director, Puget Sound Affiliate, Susan G. Komen Breast Cancer Foundation; Tara Chestnut, Program Coordinator, YWCA-Encore Plus, Tacoma; Etta Williams, Senior Services of Seattle/King County; Shelly Cooper-Ashford, Center for Multicultural Health; Karen Fennell, C.H.N, Pierce County Breast & Cervical Health Program; among others.

STATEMENT OF WORK

4. Develop spreadsheets for tracking target and accessed sample.
5. Identify target sample of women for interviews for each week.
7. Begin outreach calls to eligible referred women.

STATUS: Accomplished.

A Research Project Manager was recruited to work closely with the investigative team on the day-to-day implementation of the study, including the development of a spreadsheet for tracking the population of women. We also wanted the Research Manager to participate as a member of the Scientific Advisory Committee as well as the Community Advisory Committee.

Ms. Kathryn Bunt was hired as Research Project Manager. Under the direction of the three investigators, and most regularly with Lewis, she has assumed day-to-day responsibility for the detailed documentation of all aspects of accrual, attrition,

completion of study interviews, and the assignment of interviews to interview team members.

The investigators and Ms. Bunt designed a detailed spreadsheet that has enabled us to fastidiously track the total population of potential study participants in a population data base; track the rate of outreach, accrual, enrollment, and refusals; and track the timely allocation and completion of study interviews and transcriptions.

Under the leadership of Dr. Song, potential study participants were identified through a population-based computer data base maintained by the State Health Department in Washington. This protected data base is downloaded by Dr. Lin into a locked data base for access and use by only the study team intermediary. The data base includes code numbers, names, and phone contacts; Dr. Lin oversees and retains these locked data bases. Dr. Lin also updates these population data bases so that the total universe of all potentially eligible women meeting study criteria is kept up-to-date for use by the study intermediary. The women's name and phone contact number(s) are released to the study team interviewer only after the woman grants release to the study intermediary. If she does not grant permission to be contacted, her name and code number is never known to the study team.

A population-based interview study requires detailed attention to the identification, enumeration, and systematic contact of eligible study participants. These up-front recruitment activities often constitute a large proportion of the team's work, especially in the start up of a grant. This has also been the case with Year 01 activities for the current team.

Figure 3 summarizes the recruitment and enrollment activities for Year 01. The total population of eligible women identified was 685. Of the 685 women in the population data base, 28 women were immediately ruled out by the intermediary because their

phone contact numbers were no longer in service. The remaining 657 women were women whom the intermediary sought to contact. Of these 657 women, 290 women had non-viable phone numbers. [See Figure 1 for additional details on these 290 women.] Of the 657 women, the intermediary is still attempting to contact 192 of them. These 192 women have potentially viable phone numbers but the intermediary has yet to talk directly to the woman herself. [We chose to not leave messages for the women. Among other reasons, we fear that messages could be misconstrued, misunderstood, or create stress, none of which we want to create.]

Population of African American Women n= 685

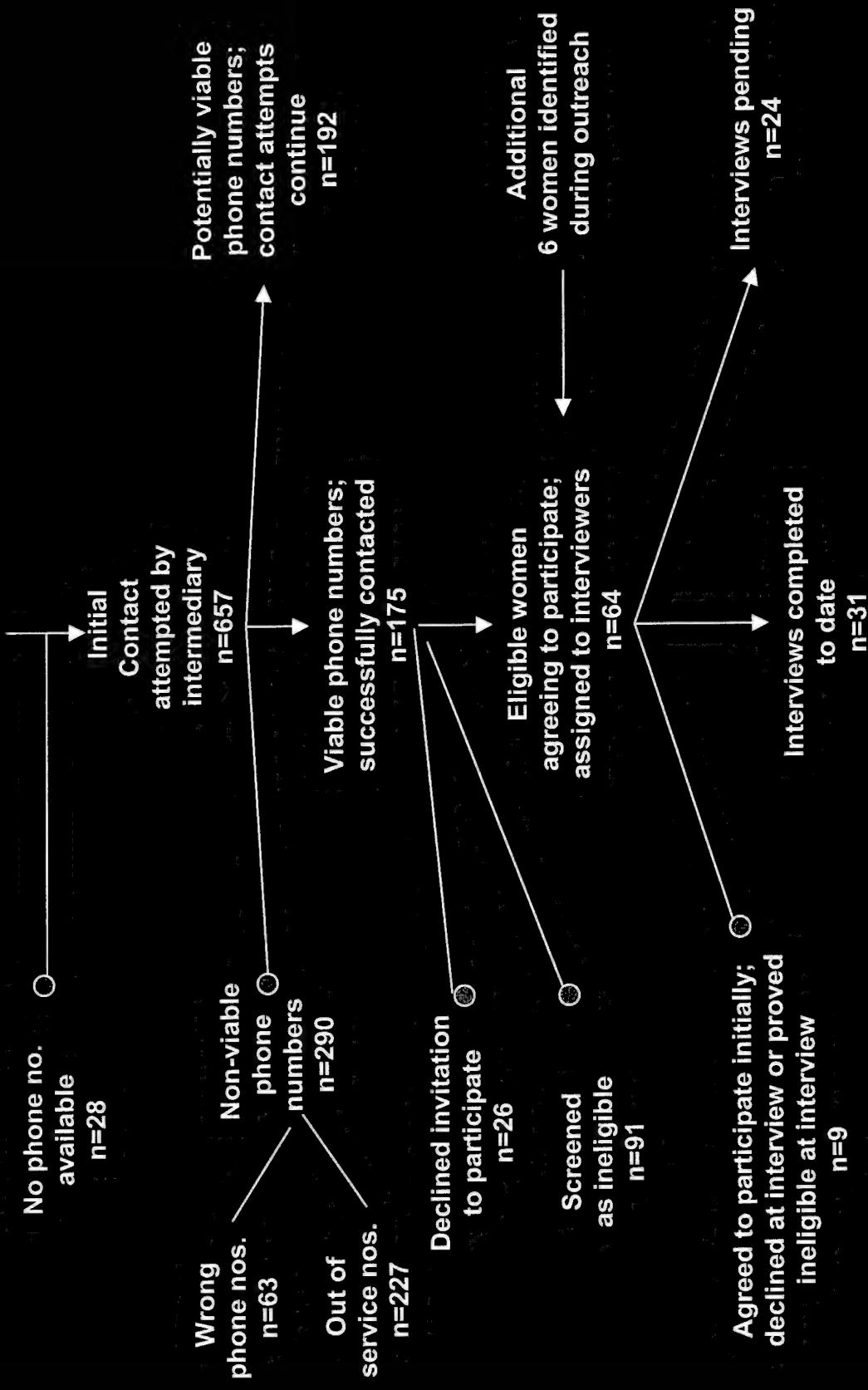


Figure 3: Population-based Recruitment and Enrollment, Year 01 Activities

Of the 559 women with potentially viable phone numbers [657-(290 + 192)], 175 women were successfully contacted by the study intermediary. Of those contacted, 26 women declined the intermediary's invitation to participate. NOTE: This small group of women are the ONLY women who explicitly refused the intermediary. This represents an initial refusal rate of only 15 % (26/175). Of the 175 contacted women, another 91 were screened out as ineligible by the intermediary based on data obtained from the initial phone contact. For example, some women said they obtained a screening mammogram from another source even though they had refused the free mammogram from the BCHP outreach worker.

Of the 175 successfully contacted women, 58 verbally agreed to have the intermediary give their name and phone number to the interviewer on the study team. During this same period, an additional 6 eligible women were identified through outreach, gave consent to be contacted by a study team interviewer, and were added to the population pool. These additional six women brought the total number of eligible women agreeing to be interviewed to 64. All six of these added eligible women were consented and interviewed by the study team. Of the remaining 58 women, 9 either declined to be interviewed after the interviewer contacted them to establish an appointment or were screened out by the interviewer as ineligible. Of the total of 64 eligible and verbally assenting women, 31 interviews have been completed to date and an additional 24 interviews are pending completion at the end of Year 01.

Although the study team has made major progress toward achieving its one-year recruitment, enrollment, and interview goals, we have learned a number of important things from our Year 01recruitment work. These are briefly described next.

Although the investigative team is pleased with the processes and timing of phone contacts to study participants, we plan to further systematize the intermediary's attempts to contact the 192 women whose phone number is viable but with whom the intermediary is yet to speak.

The population data base from which we drew our population of potentially eligible study participants included women who had been entered into the population data base up to 7 years prior (since 1994). This lengthy period of time added to the probability that the intermediary would not be able to successfully contact the potential participant. Recall that 318 numbers of the original set were non-viable [28 + 290]. This represents 46% of the women [318/685] who were essentially unavailable to us because of non-working or non-viable phone numbers. Thus in Year 01, the greatest cause of subject loss to the study were non-functioning phone contact numbers. When we reviewed the year during which the phone contacts were recorded in the population data base, some contacts were entered as far back as 1994, others from 1996 and 1997. This emphasizes the importance, in future population based studies, of not only obtaining multiple phone contacts for each woman but for updating or verifying the currency of those phone contacts over time. It also suggests the importance of including even distant family member contacts in order to reach women. Even when the intermediary had two contact phone numbers for a potential study participant, many times both numbers were non-functioning.

A total of 91 women (52%) with viable phone numbers who were successfully contacted by the intermediary were ruled out by the intermediary as ineligible. The most frequently cited reasons for ineligibility were the woman's claim that either she had not refused a free mammogram or that she had obtained a mammogram from another source during the time of the outreach by the BCHP outreach worker. This high rate of

ineligibility raises questions about two things: 1) the completeness of information stored in the population data base from which this investigative team draws this study sample; and 2) a possible self-enhancement or social desirability bias in the woman's response. We are unable, at this time, to precisely determine which type of error is affecting this unexpected rate of referral after the woman is contacted. We will be pursuing this issue more in Year 02.

As a side benefit, Ms. Bunt also applied for and has been accepted into the M.P.H. program at the University of Washington, School of Community Medicine and Public Health. Her educational advanced training will benefit the grant; her scholarship goals in that graduate program are well articulated with the activities of this Idea Grant.

STATEMENT OF WORK

- 8. Begin interviews by trained interviewers.**
- 10. Begin weekly meetings of interview team.**
- 14. Continue weekly meetings of interview team.**
- 16. Total of 56 interviews completed.**

STATUS: Accomplished 8, 10, and 14. Partly achieved 16: Completed 31 interviews + 24 pending= 55 interviews. These pending interviews represent women who agreed to have the intermediary give their name/phone contacts to the study team interviewers but whose interviews have yet to be completed by end of Year 01; they are, however, in various stages of being scheduled and conducted.

A one-day workshop was developed to train the study interviewers. Three training workshops were conducted in Year 01. We have developed a Training Manual that has been used to train all the interviewers for the current study. A copy of the Training Manual is available upon request. Lewis assumed leadership in its development; the Scientific Advisory Committee reviewed it prior to its use. Phillips-Angeles, Co-PI and Kathryn Bunt, Research Manager, have both participated in the training workshop.

Components of the Training Manual include training on signed informed consent; strategies for correctly conducting case intensive elicitation interviews, including methods that maximize the woman's unbiased description of her personal beliefs and attitudes; and methods for evaluating the quality and protocol for each interview. A quality monitoring checklist was developed specifically for this Idea Grant titled, "Criteria for a Successful Interview" and is available upon request.

Year 01 activities included outreach, hiring, and training members within the African American community to participate as study interviewers and transcriptionists. By fully engaging these community members as members of the study team, the investigators believed the community members would have the most direct and fullest knowledge of the study data; would have personal insights into the "thick descriptions" [personally elaborated text] that were offered by study participants; and would be readied for helping the study team correctly interpret and use the information from the interviews to design better outreach and breast cancer screening messages, programs, services and materials. Operationally, Year 01 work included creating formal, systematic community member participation in the funded positions of this Idea Grant.

Ellen Phillips-Angeles, Co-PI, provided major leadership in outreach and hiring community-based and indigenous staff. She organized a pivotal community-based meeting on April 14, 2000, during which the grant was fully described and we extended an open invitation to community members as full partners in all aspects of the grant. Ms. Phillips-Angeles invited recruitment agency staff, BCHP outreach workers, leaders in public health, and carefully chosen others to this meeting.

From this meeting, as well as through substantial outreach by Ms. Phillips-Angeles, we have recruited and hired 5 interviewers who are African American women: Rietta Williams and Bridgette Richardson, both community outreach workers; Carolyn

Barnett, a community resident; Tony Sills, an MSW; and Shawna Weatherbee, a Nurse Practitioner. In addition, Michele Perrin, patient educator, was hired and trained as an interviewer. Ms. Perrin is not African American but has a long history of community-based clinic work in the inner city of Mobile, Alabama with African American clients where she was exceptionally well received.

Lewis assumed leadership to meet with the study team interviewers. The initially planned weekly meetings had to be altered because the interviewers worked other jobs and needed to use their evenings, week-ends, or day time available hours to conduct the study interviews. Lewis flexed around their schedules and instead phone contacted each interviewer after each completed interview. These phone contacts served three purposes: it gave the investigative team an opportunity to support and link to each trained interviewer; it helped Lewis augment the interview skills of each of the trained interviewers; it helped identify the operational and practical issues of contacting and scheduling an interview with women who were exceptionally difficult to contact by phone; and it created a link between the interviewers and the total investigative team.

STATEMENT OF WORK

- 13. First Meeting of Scientific Advisory Council**
- 15. Second Meeting of Scientific Advisory Council**

STATUS: Accomplished

The investigators and co-investigators (Lewis, Phillips-Angeles & Song), along with the Research Manager (Bunt) and invited guests, constitute the Scientific Advisory Council. This Council met three times in Year 01 to establish the logistics for accomplishing Year 01 activities; for refining the guidelines for recruiting study participants; for protecting the confidentiality of the population data base for reviewing the Training Manual prior to its use; for overseeing the standards for training the study

interviewers; and for hiring project staff. Many of the functions we initially envisioned for the Scientific Advisory Council have been assumed by the Community Advisory Committee. This Community Advisory Committee has offered advice and direction to the science of the grant, not just its implementation.

Dr. Lin Song, Co-Investigator, provides major input at these meetings for updating the study team on the population data base. These updates relate to the numbers of women who meet study eligibility criteria, including updated information on new women who are added to the population data base. Only numbers, not identifiers, are discussed at these meetings; we protect the confidentiality of these women.] In this way, Dr. Song enables us to be continually linked with the most updated population data base for this study. This is essential because this is a population-based study.

STATEMENT OF WORK

- 9. Train Project Manager on open coding.**
- 11. Begin transcription of first set of interviews.**
- 12. Begin open coding of interviews.**

STATUS: Accomplished.

Lewis trained two graduate prepared patient educators on formal strategies of inductive content analysis. These are in addition to the Research Project Manager. Ms. Bunt's responsibilities were so extensive and linked to the operational aspects of study recruitment and spreadsheet tracking that it was important to train additional staff as well. It was clear that the investigative team needed additional assistants to carry out, under direction of the investigators, the inductive coding of the transcribed interviews. We will initiate formal coding in Year 02, using the multi-staged methods that were described previously in the research literature (Lewis & Deal, 1995).

In Year 01, we established a quality monitoring process for reviewing each interview for adherence to protocol and for adherence to standards of excellence. This

monitoring was essential to generating rigorous interviews across the different interviewers. Lewis assumed leadership for micro-monitoring the quality and integrity of these interviews, including providing feedback to the interviewers on the completed interviews.

Each interview is reviewed in two ways: for adherence to the interview schedule [in order to make each interview consistently scripted between the different interviewers] and for adherence to quality criteria. This latter review uses the criteria for interview excellence that were used in the training workshops that trained the study interviewers. Each interviewer was given a copy of these criteria at the workshop and retained a copy for their files and use. Each interviewer was also told that each interview would be monitored for consistent delivery of the interview questions as well as for the quality with which the interview was conducted.

Although formal inductive coding of the transcriptions of the study interviews has not been conducted, Lewis has been deeply engaged in the text of the interviews completed to date. This engagement was necessary for quality monitoring the interview but also for assessing whether the interview questions were yielding "thick description" of the culturally embedded beliefs and meanings about breast cancer and breast cancer screening. The interviews completed to date were very successful and have yielded pages and pages of elaborated text from the study participants. Phillips-Angeles will deeply engage in the transcribed interviews in Year 02.

Preliminary review of the open codes of the transcriptions has yielded new findings that have not been described in the research literature. We demure from reporting these early results; we do not want to prematurely "freeze" on these initial open codes. However, examples of these initial open codes were shared at the Community Advisory Committee meeting in Year 01. Members of the Community

Advisory Committee were very excited about these early codes and viewed them as important contributions to enhancing future screening programs.

Both Lewis and Phillips-Angeles will engage in and technically oversee the formal coding of the elicitation interviews in Year 02. Coding accuracy will be micro-monitored. Members of the Community Advisory Committee and other members of the community and scientific research community will be invited to participate in formal sessions to review and critique (peer debriefing) the inductively coded interviews.

Reportable Outcomes

1. A population data base of uninsured and fiscally challenged African American women can be successfully phone contacted by an unknown intermediary.
2. The initial rate of refusal to participate was lower than expected when first phone contacted by the study intermediary; only 15% (25/175) of eligible women contacted by the intermediary refused to be contacted by the study team interviewer.
3. The greatest number of women "lost" to the study was due to two factors: non-functioning phone contact numbers and ineligibility determined by phone contact by the study intermediary.
4. Community members are able to function as full partners and research team members and inexperienced community members can be successful in the conduct of case intensive elicitation interviews that meet high standards of excellence.
5. Completed elicitation interviews yielded detailed description and elaboration of participants' beliefs, perceptions, and attitudes toward breast cancer and breast cancer screening. Results from these interviews include data that have not been previously identified in the research literature.
6. A Community Advisory Committee of stakeholders and community members is able to assume a major advisory and participatory role as full community partners in the conduct and direction of this current population based interview study.

Conclusions

The systematic, population-based approach to recruiting and interviewing fiscally challenged, uninsured African American women has documented success in Year 01. Completed interviews to date have yielded thick descriptions of culturally embedded factors and beliefs that affected the study participants' decisions to decline participation in a free breast cancer screening program. Many of these factors have not been documented in prior published research.

We need to identify additional ways for the intermediary to contact the potentially eligible study participant whose phone number(s) are not viable. We "lost" too large a proportion of women to the study from the initial population data base because of the non-viability of her phone contact number(s). In contrast, the exceptionally low rate of refusal to participate when successfully contacted by the study intermediary is a positive sign; women choose to come into the study even when they had no prior contact with the study intermediary. However, we must first be able to successfully contact them. Outdated phone contact numbers was a hindrance to study recruitment.

On-going interviews were monitored for adherence to the standardized interview schedule and for adherence to quality criteria. This level of detailed review of the completed interviews enabled the study team to remain deeply engaged in both the process and the evolving content of the interviews; "thick descriptions" from the interviews, although not formally coded, provided early evidence of new cultural meanings, perceptions and beliefs that affected the African American women's decisions to not participate in free breast cancer screening programs. Many of these results, although still too early to report, have not been documented in prior research literature from this population of women.

References

- Abbott, R., Barber, K.R., Taylor, D.K., & Pendel, D. (1999). Utilization of early detection services: a recruitment and screening program for African American women. *Journal Health Care Poor and Underserved, 10*(3):269-280.
- Adderley-Kelly, B., & Green, P.M. (1997). Breast cancer education, self-efficacy, and screening in older African American women. *Journal National Black Nurses Association, 9*(1):45-57.
- Ansell, D., Lacey, L., Whitman, S., & Phillips, C. (1994). A nurse-delivered intervention to reduce barriers to breast and cervical cancer screening in Chicago inner city clinics. *Public Health Reports, 109*(1), 104-111.
- Antony, A.K. (1999). How African-American women look at breast cancer. Perceptions from rural North Carolina. *NC Medical Journal, 60*(5):284-287.
- Bailey, E.J., Erwin, D.O., & Belin, P. Using cultural beliefs and patterns to improve mammography utilization among African-American women: the Witness Project. *Journal National Med Assoc, 92*(3):136-142.
- Barroso, J., McMillan, S., Casey, L., Gibson, W., Kaminski, G., & Meyer, J. (2000). Comparison between African-American and white women in their beliefs about breast cancer and their health locus of control. *Cancer Nursing, 23*(4): 268-276.
- Bernstein, J., Mutschler, P., & Bernstein, E. (2000). Keeping mammography referral appointments: motivation, health beliefs, and access barriers experienced by older minority women. *Journal of Midwifery Women's Health, 45*(4):308-313.
- Bottomley, A., & Jones, L. (1997). Breast cancer care: women's experience. *European Journal of Cancer Care, 6*(2), 124-132.
- Bowen, D., Hickman, K.M., & Powers, D., (1997). Importance of psychological variables in understanding risk perceptions and breast cancer screening of African American women. *Women's Health, 3*(3-4):227-242.

Brown, L.W., & Williams, R.D. (1994). Culturally sensitive breast cancer screening programs for older black women. *Nurse Pract.*, 19(3):21, 25-26, 31.

Burnett, C. B., Steakley, C. S., & Tefft, M. C. (1995). Barriers to breast and cervical cancer screening in underserved women of the District of Columbia. *Oncology Nursing Forum*, 22(10), 1551-1557.

Caplan, L.S., Helzlsouer, K.J., Shapiro, S., Wesley, M.N., & Edwards, B.K. (1996). Reasons for delay in breast cancer diagnosis. *Preventive Medicine*, 25(2):218-224.

Cassard, S.D., Weisman, C.S., Plichta, S.B., & Johnson, T.L. Physician gender and women's preventive services. *Journal Women's Health*, 6(2):199-207.

Champion, V., & Menon, U. (1997). Predicting mammography and breast self-examination in African American women. *Cancer Nursing*, 20(5):315-322.

Cimprich, B. (1998). Age and extent of surgery affect attention in women treated for breast cancer. *Research in Nursing & Health*, 21(3), 229-238.

Clark, N.M. & McLeory, K.R. (1995). Creating capacity through health education: What we know and what we don't know. *Health Education Quarterly*, 22(3), 273-289.

Conn, V. S. (1997). Older women: social cognitive theory correlates of health behavior. *Women Health*, 26(3), 71-85.

Crane, L. A., Leakey, T.A., Rimer, B.K., Wolfe, P., Woodworth, M.A., & Warnecke, R.B. (1998). Effectiveness of a telephone outcall intervention program to promote screening mammography among low-income women. *Preventive Medicine*, 27(5, Pt. 2), S39-49.

Crump, S.R., Mayberry, R.M., Taylor, B.D., Barefield, K.P., & Thomas, P.E. (2000). Factors related to noncompliance with screening mammogram appointments among low-income African American women. *Journal National Medical Association*, 92(5):237-246.

Danigelis, N.L., Roberson, N.L., Worden, J.K., Flynn, B.S., Dorwaldt, A.L., Ashley, J.A., Skelly, J.M., & Mickey, R.M. (1995). Breast screening by African-American women:

insights from a household survey and focus groups. *American Journal of Preventive Medicine*, 11(5):311-317.

Davis, R. E. (1998). Coming to a place of understanding: the meaning of health and illness for African American women. *Journal of Multicultural Nursing and Health*, 4(1), 32-41.

Dolan, N. C., Lee, A. M., & McDermott, M. M. (1997). Age-related differences in breast carcinoma knowledge, beliefs, and perceived risk among women visiting an academic general medicine practice. *Cancer*, 80(3), 413-420.

Eng, E. (1993). The Save our Sisters Project. A social network strategy for reaching rural black women. *Cancer*, 72(3 suppl):1071-1077.

Erwin, D.O., Spatz, T.S., Stotts, R.C., & Hollenberg, J.A. (1999). Increasing mammography practice by African American Women. *Cancer Practice*, 7(2):78- 85.

Flynn, B.C. (1992). Healthy Cities: A model of community change. *Family & Community Health*, 15(1), 13-23.

Flynn, B.C., Rider, M., & Ray, D.W. (1991). Healthy cities: The Indiana Model of Community Development in Public Health. *Health Education Quarterly*, 18(3), 331-347.

Franzoi, S. L., & Koehler, V. (1998). Age and gender differences in body attitudes: a comparison of young and elderly adults. *International Journal of Aging and Human Development*, 47(1), 1-10.

Freudenberg, et al. (1995). Strengthening individual and community capacity to prevent disease and promote health: In search of relevant theories and principles. *Health Education Quarterly*, 22(3), 290-306.

Friedman, L. C., Neff, N. E., Webb, J. A., & Latham, C. K. (1998). Age-related differences in mammography use and in breast cancer knowledge, attitudes, and behaviors. *Journal of Cancer Education*, 13(1), 26-30.

Greenlee RT, Hill-Harmon MB, Murray T, Thun M. Cancer Statistics, 2001. *Cancer*. 2001;51(1):11-36.

Haigney, E., Morgan, R., King, D., & Spencer, B. (1997). Breast examinations in older women: questionnaire survey of attitudes of patients and doctors. *British Medical Journal*, 315(7115), 1058-1059.

Hebert-Croteau, N., Goggin, P., & Kishchuk, N. (1997). Estimation of breast cancer risk by women aged 40 and over: a population-based study. *Canadian Journal of Public Health*, 88(6), 392-396.

Heidrich, S. M. (1998). Older women's lives through time. *Adv Nurs Sci*, 20(3), 65-75.

Hoffman-Goetz, L., Mills, S.L., (1997). Cultural barriers to cancer screening among African American women: a critical review of the qualitative literature. *Women's Health*, 3(3-4):183-201.

Kagawa-Singer, M. (1995). Socioeconomic and cultural influences on cancer care of women. *Seminars in Oncology Nursing*, 11(2), 109-119.

Kalichman, S.C., Williams, E., & Nachimson, D. (2000). Randomized community trial of a breast self-examination skills-building intervention for inner-city African-American women. *Journal American Medical Women's Association*, 55(1):47-50.

Kaluzny, A. D., Rimer, B., & Harris, R. (1994). The National Cancer Institute and guideline development: Lessons from the breast cancer screening controversy. *Journal of the National Cancer Institute*, 86(12), 901-903.

Lawson, E.J. (1998). A narrative analysis: a black woman's perceptions of breast cancer risks and early breast cancer detection. *Cancer Nursing*, 21(6):421-429.

Lowe, J. I., Barg, F. K., & Bernstein, M. W. (1995). Educating African-Americans about cancer prevention and detection: a review of the literature. *Social Work in Health Care*, 21(4), 17-36.

- Mahloch, J., Thompson, B., & Taylor, M. (1998). Use of qualitative methods to develop a motivated video. *Journal of Health Education*, 29(2), 84-88.
- McDonald, P.A., Thorne, D.D., Pearson, J.C., & Adams-Campbell, L.L. (1999). Perceptions and knowledge of breast cancer among African-American women residing in public housing. *Ethn Dis*, 9(1):81-93.
- McLeroy, K.R., et al. (1995). Creating capacity: Establishing a health education research agenda for special populations. *Health Education Quarterly*, 22(3), 390-404.
- Miller, A. M., & Champion, V. L. (1997). Attitudes about breast cancer and mammography: racial, income, and educational differences. *Women and Health*, 26(1), 41-63.
- Minkler, M. & Wallerstein, N. (1997). Improving health through community organization. In K. Glanz, F. Marcus Lewis & B. Rimer (Eds.), *Health behavior and health education: Theory, research and practice, 2nd edition*, (pp. 257-287). San Francisco: Jossey-Bass.
- Nemcek, M.A. (1989). Factors influencing black women's breast self-examination practice. *Cancer Nursing*, 12(6):339-343.
- Phillips, K., Glendon, G., & Knight, J. A. (1999). Sounding board. Putting the risk of breast cancer in perspective. *New England Journal of Medicine*, 340(2), 141-144.
- Phillips, J.M., Cohen, M.Z., & Moses, G. (1999). Breast cancer screening and African American women: fear, fatalism, and silence. *Oncology Nursing Forum*, 26(3):561-571.
- Resnick, B. (1998). Efficacy beliefs in geriatric rehabilitation. *Journal of Gerontological Nursing*, 24(7), 34-44.
- Reynolds, K. D., West, S. G., & Aiken, L. S. (1990). Increasing the use of mammography: A pilot program. *Health Education Quarterly*, 17(4), 429-441.
- Rimer, B. K. (1994). Interventions to increase breast screening. Lifespan and ethnicity issues. *Cancer*, 74(1, Suppl.), 323-328.

Rothman, A. J., Salovey, P., Turvey, C., & Fishkin, S. A. (1993). Attributions of responsibility and persuasion: Increasing mammography utilization among women over 40 with an internally oriented message. *Health Psychology, 12*(1), 39-47.

Ruffing-Rahal, M. A., Barin, L. J., & Combs, C. J. (1998). Gender role orientation as a correlate of perceived health, health behavior, and qualitative well-being in older women. *Journal of Women Aging, 10*(1), 3-19.

Schwartz, A. J., Lerman, C., Hughes, C., Peshkin, B. N., & Biesecker, B. (1998). Psychological distress in women seeking genetic counseling for breast-ovarian cancer risk: the contributions of personality and appraisal. *Annals of Behavioral Medicine, 19*(4), 370-377.

Schwartz, M. D., Lerman, C., Audrain, J., Cella, D., Rimer, B., Stefanek, M., Garber, J., Lin, T. H., & Vogel, V. (1998). The impact of a brief problem-solving training intervention for relatives of recently diagnosed breast cancer patients. *Annals of Behavioral Medicine, 20*(1), 7-12.

Silliman, R. A., Dukes, K. A., Sullivan, L. M., & Kaplan, S. H. (1998). Breast cancer care in older women: sources of information, social support, and emotional health outcomes. *Cancer, 83*(4), 706-711.

Stoddard, A. M., Rimer, B.K. Lane, D., Fox, S.A., Lipkus, I., Luckmann, R., Avrunin, J.S., Sprachman, S., Costanza, M., Urban, N. (1998). Underusers of mammogram screening: Stage of adoption in five U.S. subpopulations. The NCI Breast Cancer Screening Consortium. *Preventive Medicine, 27*(3), 478-487.

Tessaro, I., Eng, E., & Smith, J. (1994). Breast cancer screening in older African-American women: qualitative research findings. *American Journal of Health Promotion, 8*(4):286-292.

Underwood, S.M. (1999). Breast cancer screening among African American women: addressing the needs of African American women with known and no known risk factors. *Journal National Black Nurses*, 10(1):46-55.

Wyatt, G. K., & Friedman, L. L. (1998). Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer. *Oncology Nursing Forum*, 26(4), 761-768.

Zapka, J. G., Costanza, M.E., Harris, D.R., Hosmer, D., Stoddard, A., Barth, R., Gaw, V. (1993). Impact of breast cancer screening community intervention. *Preventive Medicine*, 22, 34-53.

Zhu, K., Hunter, S., Bernard, L., Payne-Wilks, K., Roland, C., Everett, C., Feng, Z., & Levine, R. (2000). An intervention study on screening for breast cancer among single African-American women aged 65 and older. *Ann. Epidemiol.*, 10(7):462-463.

Zhu, K., Hunter, S., Bernard, L.J., Payne-Wilks, K., Roland, C.L., & Levine, R.S. (2000). Mammography screening in single older African-American women: a study of related factors. *Ethn. Dis.*, 10(3):395-405.